

Healthcare Professionals' Perceptions of the Barriers to Living Donor Kidney Transplantation among African Americans

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The number of African Americans participating in living donations continues to remain low. Although researchers have identified multiple barriers to cadaveric donation, relatively little is known about barriers to living kidney donation among this population. We conducted three focus groups of healthcare professionals from a transplant center in South Carolina to determine their perceptions of barriers to living kidney donation among African Americans. An African-American and a Caucasian member of the project team facilitated the groups. Sessions were taped, transcribed and analyzed for key themes. Eighteen transplant professionals participated in the three focus groups, including physicians, transplant coordinators, pharmacists and a data coordinator. Analysis of the transcripts revealed the following perceived barriers to living kidney donation among African Americans: 1) pre-existing medical conditions, 2) financial concerns, 3) reluctance to ask family members and/or friends, 4) distrust of the medical community, 5) fear of surgery, and 6) lack of awareness about living donor kidney transplantation. In addition to previously described barriers to cadaveric donation, this study identified barriers unique to living donation, such as pre-existing medical conditions, financial concerns, reluctance to ask a living donor and fear of surgery.

Key words: African Americans ■ kidney transplantation ■ living donation ■ focus groups ■ barriers

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INTRODUCTION

Racial disparities continue to be prevalent throughout many areas of healthcare, including kidney transplantation. The Organ Procurement and Transplantation Network reported that African Americans comprised 68.3% of the waiting list in South Carolina from 1988 to May 2005 and received 49.2% of renal transplants during the same period. Also during that period in South Carolina, only 20.8% of the kidney transplants performed were from living donors, of which only about one-third (33.3%) were from African Americans.¹

Numerous researchers have reported on barriers to cadaveric organ donation in the African-American community.²⁻⁶ In a pilot project, Callender and his colleagues conducted focus groups with 40 African Americans and identified five major barriers to cadaveric kidney donation. These barriers were: 1) lack of awareness about transplantation, 2) religious myths and misperceptions about donation, 3) distrust of the medical community, 4) concerns about premature declaration of death for donors, and 5) racism.² Subsequent studies confirmed Callender's results,^{4,5} while others contradicted some of his findings.^{6,7} For example, Yuen and her colleagues surveyed 163 patients at three family practice centers in the Bronx in a racially diverse but socioeconomically homogeneous community. They found a high level of support for organ donation among all racial groups and no objections based on religious affiliation.⁶ Pradel and her associates at the University of Maryland conducted focus groups with a racially mixed group to explore donors' and recipients' attitudes toward living donor kidney transplantation. They found all participants had a positive attitude toward living donor kidney transplantation. The main perceived barrier was the potential recipients' reluctance to accept the donor's offer.⁷

Researchers in Sweden conducted interviews with 12 potential donors to identify their motives in donat-

ing a kidney.⁸ While not specifically addressing barriers related to race, the study did identify “factors of concern” for donors. Two related to our study were: fear of not passing the medical screening and awareness of personal medical risks. Some researchers also report a concern being financial hardships created by living donation,⁹⁻¹¹ while others reported potential recipients reluctant to ask family members and friends to donate living organs.¹² Finally, some researchers found African Americans did not hold as high an opinion of transplantation as whites, in part because of what African Americans viewed as lack of fairness in the transplant process.¹³ A few researchers have studied healthcare professionals’ attitudes and knowledge about organ donation, but these studies related primarily to cadaveric donation.^{14,15}

Davis and Randhawa conducted 11 focus groups in black African and black Caribbean communities in the United Kingdom to assess awareness of and attitudes toward organ donation. They found a lack of available information in the black communities leading to low levels of awareness about organ donation and transplantation.¹⁶ Switzer and his colleagues studied factors associated with ambivalence among newly recruited bone marrow donors of all races. Their research identified concerns about finances, missing time from work, fear of procedure, pain and lack of information.¹⁷

Given the broad range of issues and the lack of a standardized approach to identifying barriers to donation, little comparable information exists on barriers to living kidney donation among African Americans. Thus, the purpose of our study was to explore the perceptions of transplant center healthcare professionals about barriers to living kidney donation among African Americans in South Carolina. In this article, we report the results of three focus groups with transplant center staff at the Medical University of South Carolina (MUSC) in Charleston.

MATERIALS AND METHODS

Study Participants

We conducted three focus groups with an interdisciplinary, multicultural group of healthcare professionals at MUSC to determine their perceptions about barriers to living organ donation. Participants were recruited from among transplant center staff, who were informed by memo and word of mouth that three focus groups would be held at different times and dates over the course of two months. The memos stated that focus groups would be held to discuss the living kidney donation program and that participation was voluntary. Participants were not told that we were particularly interested in surveying their perceptions of the barriers to living kidney

Table 1. Focus group script

Please tell us your *fictitious* name, occupation and role within the transplant division.

1. A. How do you think having a kidney transplant affects a person's life?
(Clarify positive and negative ideas as they are heard, then summarize and probe for anything further)
 Prompt: Personal experience (i.e., friends, family members, etc.)
 B. How did it affect their lives? Describe good/bad and reasons.
2. What concerns do you think surround potential donors?
 Probes: Pain, financial costs/insurance coverage, time away from work, distrust of medical system, attitudes towards hospitals/doctors, etc.
3. Are there different concerns for potential donors who are African American?
 Probes: religious concerns, same ethnic group coordinators and role models.
4. What would potential donors need to know before making a decision?
 Probes: Medical procedures, where to go, who to contact, support issues, etc.
5. Describe some ways that this type of information (discussed in #4) might be best communicated to potential donors.
 Probes: Format of materials (public service announcements, print, billboards, etc.)
 Communication channels (community agencies, churches, stores, doctors' offices, etc.)
6. What strategies should be used to recruit potential donors?

Closing Question:

7. Is there anything else you would like to talk about?

transplantation among African Americans.

The program coordinator handled the logistics of the sessions, such as recruiting, making follow-up telephone calls, and providing an appropriate environment and equipment for the groups. During recruitment, efforts were made to balance the professional disciplines across the groups, with each group having all aspects of the transplant center healthcare team represented as much as possible (nephrologists, transplant surgeons, nurse coordinators, transplant pharmacists and other personnel). The participants in this study included a diverse work group of healthcare professionals with broad domestic and international training and experience in living kidney transplantation. The participants also have many years of experience in working with potential recipients and donors in hospitals and other settings, giving them insights into barriers to living kidney donation. Transplant coordinators often travel to other sites in South Carolina to offer educational programs for potential recipients and donors. The number of participants in each group was limited to seven people. The MUSC Institutional Review

Board approved all aspects of this investigation, and the study adhered to the tenets of the Declaration of Helsinki.

Procedures

Focus groups were planned and facilitated by an African American and a Caucasian, both with focus group expertise. Based on their experience, the focus group literature and suggestions from a consultant, facilitators developed a script, including the questions and prompts or probing questions. This was to ensure all groups were given the same introduction and asked the same questions. Questions dealt with the general concerns of all potential donors and specific concerns and perceived barriers for African-American donors. Facilitators did not start with specific questions about barriers because they wanted to see what participants spontaneously answered. However, prompts and probing questions did address specific barriers (Table 1).

Focus groups were offered at three different times on different dates in the MUSC Transplant Center. Holding focus groups in a meeting room with a roundtable guaranteed eye contact and inclusion of all participants. During the introduction, the African-American facilitator asked participants to use fictitious names during the session for transcription, and participants consented to audiotaping the session. Two tape recorders (transcribers) were used. Participants completed questionnaires about their demographic information. The African-American facilitator led the session, following the script, asking the questions and occasionally probing for clarification. The white facilitator further queried the participants during the discussion, ran the tape recorders and took notes. At times during the interaction, the primary facilitator summarized the main points and asked for confirmation or clarification. Each session lasted approximately 90 minutes.

Transcript Analysis

A transcriptionist transcribed, compared and compiled the recordings from both tape recorders into one official transcript for each focus group session. Both facilitators reviewed the final transcripts to ensure accuracy. Three data specialists and the facilitators independently analyzed the transcripts to identify recurrent themes. In reviewing the transcripts, they looked for key phrases and statements.^{18,19}

RESULTS

Demographics

The focus group participants were an interdisciplinary, multicultural group of transplant healthcare professionals. A total of 18 individuals participated

Table 2. Demographic characteristics of focus groups composed of 18 interdisciplinary, multicultural healthcare professionals at the Medical University of South Carolina

	n	%
<i>Education</i>		
Associate's	1	5.5
Bachelor's	5	27.7
Master's	3	16.6
Doctorate	8	44.4
Professional/Technical	1	5.5
<i>Profession</i>		
Data Coordinator	1	5.5
Transplant Coordinator	6	33.3
Nurse Practitioner	1	5.5
Fellow (Transplant Surgery)	1	5.5
Pharmacist	2	11.1
Physician	4	22.2
Transplant Surgeon	3	16.6
<i>Race</i>		
African American	1	5.5
Asian/Pacific Islander	4	22.2
Caucasian	13	72.2
<i>Ethnicity</i>		
Hispanic Latin	1	5.5
Non-Hispanic	15	66.6
Not indicated	2	11.1
<i>Gender</i>		
Women	7	38.8
Men	11	61.1

in three focus groups, with each group including 5–7 people. Participants included eight physicians (four nephrologists, three transplant surgeons and one transplant surgery fellow), six transplant coordinators, one nurse practitioner, two pharmacists and one data coordinator. Each group was similarly balanced in representation of different disciplines. Twelve of the participants were non-Hispanic Caucasian, four Asian, one African-American and one Hispanic (Table 2).

Perceived Barriers

In the focus groups, transplant healthcare professionals identified what they perceived as barriers to living kidney donation among African Americans in South Carolina. Barriers emphasized were: 1) pre-existing medical conditions, 2) financial concerns, 3) reluctance to ask family members and friends, 4) distrust of the medical community, 5) fear of surgery, and 6) lack of awareness about living donor kidney transplantation.

Pre-existing medical conditions. While participants did not prioritize barriers, this barrier was brought up early during all three focus groups. According to the participants, the lack of available living donor kidneys is due in part to pre-existing medical conditions in the African-American population, making potential donors medically ineligible to donate. Conditions such as diabetes, high blood pressure or intrinsic kidney disease are highly prevalent in the African-American community and lead to a scarcity of qualified donors. This point is emphasized by one participant's comment: "A lot of them have hypertension and diabetes that run in their families, and a lot of them are on dialysis together."

Financial concerns. Focus group participants said they heard potential recipients and donors express concern about such issues as loss of time at work, loss of job, lack of transportation to the transplant center for tests and an inability to get insurance after donation. Participants said hourly employees were afraid they would lose pay when donating their kidney or may lose their employment due to their physical inability to work. Two statements were representative:

- "Economics plays a role. If you are in a job situation where physical labor is what you have to do to earn your living, then obviously undergoing any kind of operation could potentially cause you not to be able to resume that job."
- "People worry about their medical insurance. Will they be able to get medical insurance if they have only one kidney?"

Reluctance to ask. Participants talked about the

reluctance of potential recipients to ask family members and friends to make such a sacrifice. According to individuals in the focus groups, African Americans appeared more reticent about asking for or accepting a loved one's kidney. They were also less likely to come forward to volunteer and less likely to be willing to initiate discussion about transplantation among family members.

Typical comments addressed such issues as a potential recipient's or donor's worry that the donor might some day have kidney failure him or herself or the donor's child might need a kidney in the future. Following are representative statements.

- "They don't want a kidney from their friend or their daughter, and they don't want to hear about it and that's the end."
- "They don't want to ask their two or three healthy kids ... they just don't want to visit that issue."

Distrust of the medical community. Participants also identified distrust of the medical community among African Americans as a barrier to renal transplantation. Participants noted that some African Americans felt whites received preferential treatment in terms of medical care. In referring to cadaveric donation, one participant said, "They might feel that Caucasians get transplanted before African Americans if they're on a list."

Asked about living donation, participants said the distrust was still there but not as much as with cadaveric donation:

I think they have a fear of who does this team have a vested interest in. Are we just after the organs or are we really making sure this is safe to do? As much as we try to calm them on that factor, I think they're afraid of that, that we just want the kidney.

Fear of surgery. Participants of the focus groups reported fears related to surgery included worries about physical and psychological changes following donation of the kidney, scarring, physical complications of the surgery and lack of support following the donation. Some said potential donors were concerned about whether they could have children later. Participants mentioned people wondered whether they could live with just one kidney and worried about what would happen if one day they lost that kidney as well. Few participants mentioned pain or death as major concerns for potential donors, but some participants said potential recipients worried about the pain their loved ones might suffer if they donated.

Lack of awareness about living donor transplantation. A recurrent theme in the focus groups was African Americans, particularly those who are

less educated, do not have complete or accurate information about the transplantation process when they present for evaluation. A transplant coordinator said: "They don't understand that they're getting off of dialysis and they're getting a transplant and have to take all of these medications and have to get labs all the time ... It's more involved than they understand."

Participants said some potential recipients referred for evaluation are not aware of living donation and laparoscopic surgery as options. In addition, some potential recipients and donors are not aware of the advantages and disadvantages of transplantation. In part, participants said, this lack of awareness is due to lack of access to healthcare and to healthcare information, particularly in rural areas.

Religious concerns. When the facilitator specifically asked whether potential patients or donors had any religious objections to living donation, participants in our focus groups did not believe religion was a barrier. One participant (the only African American) made a comment reflecting the general opinion: "Surely by the time the issue is brought up, I guess they have made up their mind to do something ... They may be on the fence, and they just need someone to push them over. I don't think we have had anyone who for religious reasons refused."

Same Race or Culture Role Models

This issue was not brought up as a specific barrier to living kidney donation among African Americans. However, when the facilitator asked how best to recruit living donors, participants made these representative comments. The first three statements were from female nurse coordinators. The last two comments were from male physicians.

- "One of the things I think might help...is having an African-American donor and recipient out in the community, attending functions where African Americans are likely to attend ... to increase knowledge of transplant donation."
- "I totally agree with her in that the whole thing about this is to have role models and if you have role models in a particular race, then it's not incorrect to do that. I mean, if it's going to allay fears and mistrust, I think it should be welcome and it should happen."
- "I think there should be more outreach into the communities ... There are actually different cultures in the different parts of the state—different cultures that need to be educated differently."
- "In my country, where I come from, where we've got a zillion different languages and a zillion different religions, I've always noticed

that in my team, even when I was chief resident, if I had an intern who spoke the same language as the person or was of the same religion as that person, [patients] would have greater trust in that doctor's ability than anyone else on the team."

- "That issue, I don't think it makes much of a difference because in one of the best, very successful living donor programs in the country, their coordinators are both Caucasians. They have one of the largest [success rates] for cadaveric or living donation in African Americans in the country, probably in the world ... So I don't think it makes much of a difference, by my own experience."

Several participants agreed with the latter statement.

DISCUSSION

Most of the findings from our focus groups on living kidney transplantation were consistent with those of the research on cadaveric transplantation.^{2,5,11,13,15} Analysis of the focus group transcripts revealed the following perceptions of barriers to living kidney donation in the African-American population: 1) pre-existing medical conditions, 2) financial concerns, 3) reluctance to ask family members and friends, 4) distrust of the medical community, 5) fear of surgery, and 6) lack of awareness about living donor kidney transplantation. Implications of these results are addressed below.

Pre-existing medical conditions. Since diabetes, hypertension and kidney disease are prevalent in the African-American community, promoting general health among African Americans will help increase the pool of available living donors. Numerous health promotion programs are aimed at such issues, including programs in churches and other settings. However, this barrier is complex and not likely to be easily resolved.

Financial concerns. Currently, surgery costs for most living donors are covered by the federally sponsored End-Stage Renal Disease Medicare program. Delmonico and his coauthors¹⁰ recommended that guidelines similar to those for short-term disability be established to compensate for a donor's lost wages. At the present time, the federal legislature is exploring other ways to cover donor expenses related to travel and loss of work time.

Reluctance to ask. Certainly, African Americans are not the only group reluctant to ask friends and family members to make the sacrifice of donating a kidney. Schweitzer and his colleagues in Germany also observed this concern among potential recipients.¹² Pradel and her associates found this barrier among potential recipients of all races.⁷ However, our focus group participants noted they heard more con-

cerns about recruiting from African Americans than from other racial groups. Participants suggested that transplant coordinators, other healthcare professionals, and friends and family members of potential recipients could also help in recruiting living donors. More public and grassroots education could also reduce potential recipients' reluctance to ask.

Other barriers. The rest of the barriers we found (distrust of the medical community, fear of surgery and lack of awareness about living donor kidney transplantation) confirm findings of other researchers.^{7,8,9,12} A recurrent theme in the focus groups was African Americans, particularly those who are less educated, do not have complete or accurate information about the transplantation process when they present for evaluation. Participants said some potential recipients referred for evaluation are not aware of living donation and laparoscopic surgery as options. In addition, some potential recipients and donors are not aware of the advantages and disadvantages of transplantation. In part, this lack of awareness is due to lack of access to healthcare and to healthcare information, particularly in rural areas.

These three barriers could be addressed in part by public education and by educational campaigns aimed specifically at the African-American community. Indeed, such campaigns have been shown to be successful in increasing the living donor rate among African Americans.^{7,19}

Some findings from our focus groups on living kidney transplantation did not support those in previous studies. For example, when asked whether religion played a role in whether an individual would be willing to ask for or to donate a kidney, transplant center health professionals participating in our focus groups did not believe religion was a barrier to living kidney donation among African Americans. This result agreed with the findings of Yuen and her colleagues related to cadaveric donation.⁶ Our focus groups were with healthcare professionals working primarily with individuals presenting to be evaluated for transplantation and their families. Therefore, it may be these individuals already dealt with any religious misgivings about the procedure. In addition, since only one African American participated in the focus groups and he was the one who made the comment quoted in the methodology section about there being no religious reservations, perhaps other participants were reluctant to disagree with him. Therefore, it would be worthwhile to continue to explore what role religion has in transplantation decisions in the African-American community.

A strength of our study is it is one of few to explore transplant healthcare professionals' perceptions of the barriers to living kidney donation among African Americans. Our study also confirms perceived barriers to living donation for all populations, including

African Americans.^{7,8,10,12,16,20} Some of the barriers we identified are similar to those Switzer and his associates found in their research on unrelated bone marrow donors—finances, missing time from work, fear of procedure, pain and lack of information.¹⁷

One limitation is that our study only addressed the perceptions of a small group of transplant healthcare professionals in South Carolina. In addition, only one African American participated in the focus groups. However, the participants in this study included a diverse work group of healthcare professionals with broad domestic and international training and experience in living kidney transplantation. The participants also have many years of experience in working with potential recipients and donors in hospitals and other settings, giving them insights into barriers to living kidney donation.

Therefore, the results of the focus groups are a first step in identifying the barriers perceived by healthcare professionals to living kidney donation among African Americans. Further research needs to confirm these perceptions and should address the attitudes of transplant health professionals, the general public, and potential recipients and donors toward living kidney donation and determine the best practices to increase the pool of living donors among African Americans and other racial groups. Further research could also build on the existing research related to educational programs designed to inform and recruit African Americans willing to donate and receive living kidneys.

CONCLUSION

This study is one of only a few that has explored perceived barriers to living kidney donation among African Americans. The findings are consistent with much of the research on barriers to cadaveric kidney donation. However, our research also identified barriers unique to living donation, such as pre-existing medical conditions, financial concerns, reluctance to ask friends and family, and fear of surgery. The findings suggest much more work needs to be done to explore and overcome barriers to living donation among the African-American community.

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